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Patients assess the Patient's Card

Results of the Survey among Patients Groups concerning the Pilot Project Patient's Card Koblenz/Neuwied

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Abstract. Since Summer 1995, a pilot project on patient's card is running in Neuwied/Germany (*Pilot Project Patient's Card Koblenz/Neuwied*). From February till March 1997 we carried out a telephone survey among local patients groups in Koblenz and Neuwied. The main aim of the survey was to find out, what do the patients groups know regarding the patient's card in general and regarding the local pilot project - and what is their attitude towards it. The results of our survey should be of interest for the introduction of patient-related card systems, because serious deficits in the information policy of the project initiators became evident.

1. What kind of role plays the patient in developing the Patient's Card ?

"Where is the Patient in Patient-centered and User-oriented Design in Health Care Systems Development?" - this question was asked at the Participatory Design Conference, 1996 in Cambridge MA ([1]).This is also the leading question of a research project at the Technical University of Darmstadt which focuses on patient's role in the development and assessment of the patient's card ([5] - [8]). The main aim of our research was to find out patient's interest in evaluating and designing the health card, and to encourage them to safeguard their interests in designing technology of the health care system.

It has been always insisted from the initiators of several health card projects that the main purpose of introducing the medical card systems is for the benefit of the patients. But there is no broad consent regarding this in society: The patient's card is not assessed positively from all social groups. Due to introduction of the German Health Insurance Card in 1994, the group *Association of Alternative Patient Offices* in Germany is taking efforts to discuss not only the prospects and promises but also the social risks of this new technology ([2]). One of the main aims of this group is to criticize the structural problems of the Health Care System. Besides this there are many other patients groups those could have participated in this discussion.

Since 1995, a project on health cards is running in Neuwied/Koblenz. It is initiated by the *Kassenärztliche Bundesvereinigung* (*National Association of Health General Practitioners*), *Kassenärztliche Vereinigung Koblenz* (*Local Association of Health General Practitioners,*

Koblenz) and the *Bundesverband Dt. Apothekerverbände* (*Federal Group of German Pharmacists Associations*). Aim of this project is to define and design the health card from professionals point of view ([4]).

Since November 1995 till March 1997 we discussed with various patients groups (e.g. *Association of Rheumatic Patients*, *German Association of Haemophilics*, *AIDS-Aid* etc.) regarding the interests on the Patient's Card Koblenz/Neuwied explicitely from the patient's point of view (for discussion on designing possibilities from patient's view, see [8]).

After one year of practical work with local patients groups in Koblenz ([3]), the Participation Project was enclosed by conducting a survey. Our main aim was to find out the knowledge and opinions of the patients groups (if possible all the groups) on the Pilot Project Patient's Card, Koblenz/Neuwied and on the concept "Patient's Card" in general.

It is obvious that patients groups are only a minority of the whole social group "patient". The majority group, which is not included in patients groups, is really difficult to reach. Their interest on "patient's card" is probably very less. So we were searching for "active" patients, who are familiar with problems in the Health Care System, with its actors and the relevant phases of "policy-making". Such type of patients must be of interest in assessment and participatory design of the patient's card. This survey was not meant to represent the entire social group as "patient" but to represent active patients through patients groups. There are several methods available to achive representativity of the entire social group "patient" (e.g. *Citizen Planing Cell* in Germany, *Consensus Conferences* in Danmark, see also [1]).

2. Carrying out the survey

In January 1997, from the available 70 addresses we selected 52 groups. The criteria for selection was mainly the groups concerned with patient's card (e.g. the group *Anymous Alcoholics* is not choosen for survey because it is obvious that patient's card is not very relevant for them). For several groups of the same scope (like many *groups on diabetes*), there was an arbitrary selection between them.

Table 1: Information about the Groups

Patients groups ...	Number
listed groups in Koblenz and Neuwied	~ 70
- groups which were invited for the survey	52
- groups which participated in the survey	**33**
- groups which refused to participate	10
- groups which were not reachable	9

The selected patients groups got written invitation enclosed with an information regarding the survey. The groups choosed their representatives for the interview. We conducted the survey from February 1997 till March 1997. One interviewer from the University of Koblenz-Landau interviewed the representatives (interviewees) of the patients groups over the phone. Each interview took on an average of one hour.

The addresses of all the local patients groups in Koblenz and Neuwied were available in the Public Health Offices of Koblenz and Neuwied, and the Ministry of Health Rhineland-Palatinate.

Table 2: Some selected groups

Dialysis Groups	Society of Rheumatic Patients
AIDS-Aid Koblenz	Group of the Parkinson Disease

	patients
German Society of Haemophiliacs	Working Group of spina bifida
Diabetes Groups	German Asscociation of Asthmatics
Selfhelp Group on Osteoporeosis	Group of Women Cancer patients
Group of pregnant women	Association for blinds

Most of the local patients groups are organized under the *German National Working Association Aid for Disabled Persons* (the federal parent organisation of patients groups in Germany). These groups are well organized, having normally more than 100 members, with own executive board and statutes (e.g. the *German Society of Haemophilics*). Other interviewees were from small self-help groups (e.g. local *Diabetes Groups*), which are mostly supported by the local Health Insurance and Public Health Organizations. The third category is of independently organized patient's associations, i.e. these differentiate from others in economical and political aspects (like the above mentioned *Alternative Patient Offices*).

3. Structure of the Questionnaire

The Questionnaire, which was the basic tool of the survey, was designed with the suggestions of members of patients groups. The interviewer was guided on the interview-situation by preformed, strucured questions and flow-charts, which helped him to carry out all interviews quickly and in a uniform way.

The questionnaire consists of four parts:

1. Structure of the patients group (8 questions)
2. Knowledge of the patients groups on Health Insurance Card, Patient's Cards in general and the Pilot Project (9 questions)
3. Opinions and Assessments of the patients groups about the Patient's Cards and the Pilot Project (14 questions)
4. Further suggestions of the patients groups regarding information and participation on the concept Patient's Cards and the pilot project (8 questions).

The questionnaire includes approx. 40 questions. Due to unexperienced participants, it was not possible to evaluate the entire questionnaire. As a result several interesting questions on the Patient's Card and on the Pilot Project remained unanswered.

4. Results of the Survey

The results of the survey are presented in order of appearance of the questions in the questionnaire: Basic Information about the groups (see above), Knowledge, opinions and further suggestions.

The data in all tables is presented in absolute frequency (the number of participants was too small to give precise relative frequencies). But the comments on the tables are represented in terms of relative frequencies to give a better orientation on the distribution of results.

4.1 Knowledge of the patients groups regarding cards in Health Care System

Firstly, we wanted to know wheather the interviewee is familiar with chipcards in Health Care System in general. We started with questions on the German Health Insurance Card, which was introduced 1994 nationwide. Over 90% of all inhabitants of Germany possess this card. Also we wanted to know, wheather the interviewee is familiar with concepts of the (medical) patient's card.

In a second question participants had to enumerate data items, which are stored on the Health Insurance Card. The counted numbers of right answers shows, that they were well informed about the data structure of this card (table 3). It was to the knowledge of all the participants that no medical data has been stored on the Insurance Card.

Table 3: Which Data Items are stored on the Health Insurance Card?

Number of items	Answers
1 - 2	7
3 - 4	16
5 - 6	3
Unanswered	7
Total	33

In comparison to their knowledge on Health Insurance Card, only few interviewees knew about other kind of card applications in Health Care System (table 4). Only one participant could explain a concrete card application.

Table 4: Do you know other card applications used in Health Care System?

Yes	No	Total
10	23	33

Additionally, no participant knew anyone, who was using the patient's card and even very few knew about the pilot project in Koblenz / Neuwied (table 5) and could give some information on it (e.g. knowledge about the involved associations). So one can come to the conclusion that these groups have no clear concept of the patient's card.

Table 5: Do you know the "Pilot Project Patient's Card, Koblenz/Neuwied"?

Yes	No	Total
3	30	33

4.2 Opinions and Assessments concerning cards in Health Care System

Though the participants were not having real knowledge on patient's card, we wanted to know about their general opinions and assessments on it (see chapter 4.1). Their opinions and assessments to this were rather optimistic than pessimistic. More than 65% of the participants evaluated the patient's card rather useful, whereas 15% feared of negative consequences (table 6).

Table 6: What is your assessment on patient's cards in general ?

Attribute	Answers
useful	9
rather useful	13
undecided	6
rather harmful	1
harmful	4
Total	33

Restricting the assessment on patient's cards for their own clientele, only 45% of the interviewees assessed the patient's card useful for their own group and 25% assumed, that it would be rather harmful (table 7). By comparing positive answers in table 6 and 7, it is surprising that the u*seful assessments* of cards in general are better evaluated than the assessments for their own group. It can be assumed that for their illness computer / smart card technology doesn't play an important role in patient's everyday life.

Table 7: What is your assessment on patient's cards for your group ?

Attribute	Answers
useful	6
rather useful	9
undecided	6
rather harmful	4
harmful	5
no answer	3
Total	33

Additionally, concrete reasons for their assessments were asked which are listed in table 8.

Table 8: Some arguments in assessing the patient's card

Pro	Contra
Data available in case of emergency	Misuse is possible
Correctness and quick availability of the data	Categorized patients
Data is stored securely and only available for authorized persons	Threat on Privacy
Data available for changing the physician	costs too high for cards
Data useful to control physicians	Physicians and pharmacists want to earn too much money with the patient's card
Reducing repeated medical tests	Cards are useless
Safety of the patient	It is not possible to store all medications
Reduction of costs	Threat on discrimination
You can inform yourself	"transparent" patient

Further question is regarding the assessment of storable medical items on patient's card (table 9). Though not having much idea of card applications, the interviewees were having precise concept of the data which can be stored on a typical patient's card (e.g. data on allergies and vaccination are better storable on a card than X-ray-pictures). This indicates that the interviewees are aware of the use of card applications. This may focus on further requirements of the participants concerning data items stored on patient's cards.

Table 9: Which kind of data can be stored on the patient's card ?

Kind of data	answers			Total
	yes	no	una.[1]	
vaccination	33	0	0	33
blood group	33	0	0	33
names and addresses of patients, relatives and physicians	32	1	0	33
allergies	30	2	1	33
telephone numbers of patients, relatives and physicians	29	4	0	33
chronical diseases	29	3	1	33
disabilities	23	7	3	33
diagnosis	21	10	2	33
therapies	19	11	3	33
X-ray pictures	18	10	5	33

4.3 Further suggestions regarding information and participation

This section discusses the requirements of patients groups regarding information, discussion and participation of the patient's card. Table 10 shows that majority of the groups are very much interested in detailed information and discourses on patient's card. The positive opinions of the participants regarding information transfer between various groups (patients, physicians and others) may indicate that the patients groups are willing to engage in supporting and improving patient's card in all aspects.

Table 10: Information Requirements about the patient's card.

Question	answers			total
	yes	no	una.[1]	
Do you want more information on patient's cards ?	26	7	0	33
Would you support the publication on information on patient's cards in your group?	24	8	1	33
Would you support lectures and discourses on patient's cards in your group?	19	12	2	33

The majority of the interviewees also believed that "participatory design" is useful to consider requirements from the patient's point of view explicitely in the card projects (table 11). Additionally, although most of the interviewees agreeed on the participation of designing patient's card but no one could suggest how to realize it.

Table 11: Participation of patient's representatives in card projects ?

Question	answers			Total
	yes	no	una.[1]	
Do you wish that patient's requirements are considered in the projects explicitely ?	22	3	8	33
Do you believe that participation of patient's representatives in the projects on patient's cards is meaningful?	21	10	2	33

[1] una.: unanswered

5. Conclusion

This survey could only give a snapshot about the knowledge and opinions of patients groups regarding patient's cards in the area of Koblenz/Neuwied. Additionally, these findings among "experts" in Health Care System should not be mixed up with the knowledge and opinions of "the patient" in general (see discussion in chapter 1).

The results of the survey can be summarized as follows:

- Almost all the asked groups were hardly knowing about the concept "patient's card" in general, as well as the Pilot Project Koblenz/Neuwied.
- The groups were interested in knowing more about the patient's cards.
- In general all the groups evaluated patient's cards positively rather than negatively.
- According to the patients groups participation in such projects is important.

The results show that less than 30% of the participants were knowing about the patient's cards, and even less than 10% were informed about the Pilot Project. It can be assumed that the level of knowledge in the society is even lower than in the patients groups.

Such type of projects should not be lead as "marketing gag" or as "political weapon" of a single group (see discussion about "interest oriented design" in [8]), but as a broad social discourse. The attentiveness of the population is necessary in order to participate in such type of projects. For that project initiators should offer corresponding participatory models. This allows to gain necessary faith in the society for new innovative technical concepts like patient's cards.

6. References

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